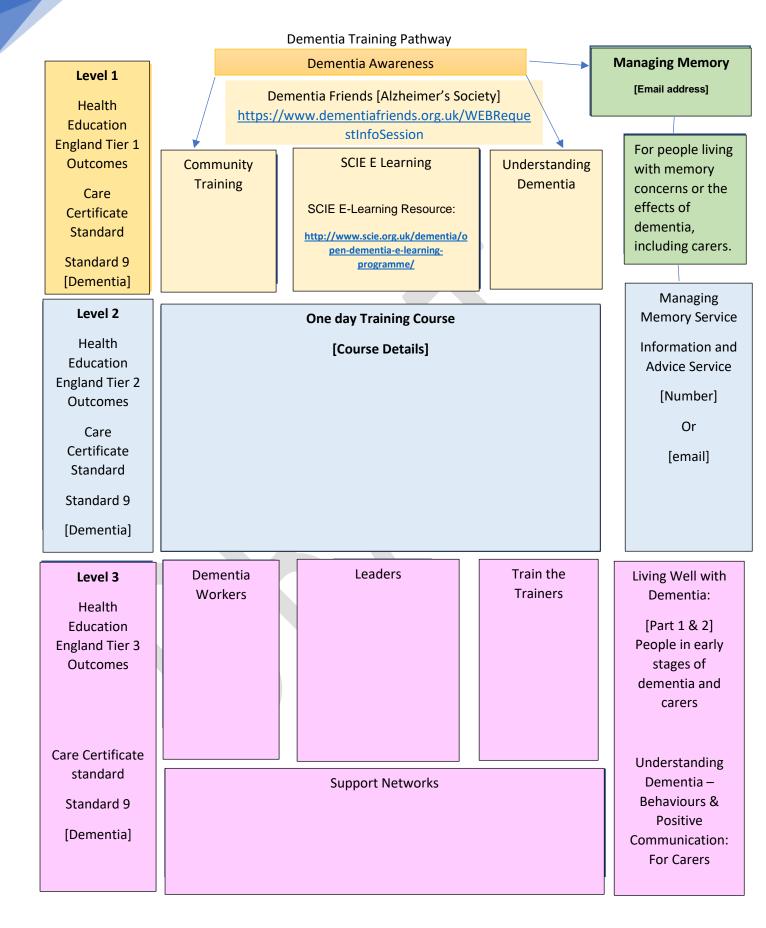
# DEMENTIA TRAINING STANDARDS FRAMEWORK 2020 TO 2023

Sandwell Metropolitan Bourgh Council & Sandwell and West Birmingham Clinical Commissioning Group

The Dementia Training Standards Framework commissioned by the department of Health and produced by Skills for Health, Health Education England and Skills for care has been adopted across Sandwell and West Birmingham

Maxine Groves

# **Dementia Training & Education Strategy Sandwell**



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# Introduction

# Background

Sandwell Metropolitan Bourgh Council [MBC] and Sandwell and West Birmingham Clinical Commissioning Group are committed to improving services for people with memory concerns, dementia and carers. Education and training features highly within this commitment and as a result the Dementia Training Standards Framework has been formally adopted.

The Dementia Training Standards Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England (HEE) in partnership with Skills for Care [2018]. The Framework supports implementation of the HEE mandate and the objectives for education, training and workforce development set out in the Prime Minister's Challenge on Dementia 2020. In particular, the aim is to support the development and delivery of appropriate and consistent dementia education and training for the health and care workforce.

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# Scope of the Framework

The care pathway for a person living with dementia, their families and carers will involve a workforce that is extensive and diverse, including many staff closely engaged in providing clinical care as well as offering information, support and assistance. This care may be offered in a broad variety of settings including an individual's own home, community settings, residential care homes and acute hospitals. In addition, care may be provided by support staff and other individuals who interact with those affected by dementia and who therefore need to have an awareness and understanding of the specific needs of people living with dementia and those of their carers.

Understanding the central role that their home, housing conditions and immediate community play in enabling a person with dementia to live well is crucial. The framework includes elements in each tier which will enable the workforce to improve their understanding of and partnership working with the housing sector. Equally, the framework will also be helpful for staff in housing settings to improve joint working with the health and social care sectors.

The Dementia Training Standards Framework is structured in three tiers to reflect the scope of HEE's principal mandate requirements. With increasing levels of integration between health and social care services and their respective workforces, it is also important to recognise how the Framework relates to the different workforce groups within social care as summarised on the table below:

HEE Tier	Match Social Care Workforce Group				
Tier 1	Group 1				
Dementia awareness raising, in terms	All of the social care workforce –				
of knowledge, skills and attitudes for all	dementia awareness				
those working in health and care settings					
Tier 2	Group 2				
Knowledge, skills and attitudes for roles	People working in social care who are				
that have regular contact with people living	providing personalised direct care and				
with dementia	support to people with dementia				
Tier 3	Group 3				
Enhancing the knowledge, skills and	Registered managers and other social care				
attitudes for key staff (experts) working with	leaders who are managing care and				
people living with dementia designed to support them to play leadership roles	support services for people with dementia				
	Group 4				
	Social care practice leaders and managers				
	who are managing care and support				
	services and interventions with people with				
	dementia which includes social workers,				
	and occupational therapists working in				
	social care				

**NB.** This Framework aims to describe core skills and knowledge i.e. that which would be transferable and applicable across different types of service provision. Additional learning outcomes may be locally determined to meet education and training needs in specific settings e.g. according to local context, risk assessment or policy.

# Structure of the Framework

The Framework is presented in 14 subjects - each subject comprises:

- an introduction
- suggested target audience
- key learning outcomes
- links to relevant guidance and/or legislation

• links to relevant national occupational standards, skills frameworks and regulated qualifications components.

# **Appendices include:**

- sources of further guidance
- user guide
- links to relevant standards, curricula and qualifications
- suggested standards for training delivery
- guidance on frequency of refresher training or assessment

### **Benefits of the Framework**

The Framework is applicable to employers, their employees and also to educational organisations that train students who will be employed in the range of health and care settings. Use of the Framework will support organisations to:

- standardise the interpretation of dementia education and training
- guide the focus and aims of dementia education and training delivery
- ensure the educational relevance of dementia training
- improve the quality and consistency of education and training provision.

The Framework also supports the assessment of competence, training needs analysis and provision of minimum standards of performance within performance management systems (e.g. as part of supervision or appraisal). Further guidance on using the Framework is available in Appendix 2.

		Target Audience						
Subject		Tier 1	Social care workforce Group 1	Tier 2	Social care workforce Group 2	Tier 3	Social care workforce Group 3	Social care workforce Group 4
1	Dementia Awareness							
2	Dementia identification assessment and diagnosis			•	•	•	0	0
3	Dementia risk reduction and prevention				•			
4	Person-centred dementia care						•	
5	Communication, interaction and behaviour in dementia care			•	•	•	•	•
6	Health and well- being in dementia care				•	•	0	0
7	Pharmacological interventions in dementia care				•	•	0	0
8	Living well with dementia and promoting independence			•	•	•	•	•
9	Families and carers as partners in dementia care				•	•	•	
10	Equality diversity and inclusion in dementia care			•	•	•	•	•
11	Law, ethics and safeguarding in dementia care			•	•	•		•
12	End of life dementia care							
13	Research and evidence-based practice in dementia care			•	•		•	•
14	Leadership in transforming dementia care					•		•

Key:  $\bullet$  = Fully applicable  $\bigcirc$  = Partly applicable

### Tier 1

Raising dementia awareness, in terms of knowledge, skills and attitudes for all those working in health and care settings.

Relevant to the entire health and care workforce including ancillary staff. This could form part of induction training and also provide a foundation for more advanced practice.

Matched to social care **workforce group 1** i.e. all social care staff including those not providing direct care and support such as catering, maintenance or administration staff.

### Tier 2

Knowledge, skills and attitudes for roles that have regular contact with people living with dementia.

Relevant to all health and care staff in settings where they are likely to have regular contact with people affected by dementia. This also underpins the more specialist skills and knowledge required at tier 3.

Matched to social care **workforce group 2** i.e. social care staff directly providing care and support which would include care assistants working in residential or home care and also personal assistants.

### Tier 3

Enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia and designed to support them to play leadership roles.

Relevant to staff working intensively with people affected by dementia including those who take a lead in decision making and developing or disseminating good practice.

Matched to social care workforce groups 3 and 4 i.e.

Registered managers and other social care leaders includes operational managers who have responsibility for services which provide care and support to people with dementia. Social Care practice leaders, managers and a range of key staff including social workers who work intensively with people affected by dementia including those who take a lead in decision making and developing or disseminating good practice. Staff in this group will use the framework in conjunction with their relevant professional standards.

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# Subject 1: Dementia awareness

**NB.** These core learning outcomes for dementia awareness may be supplemented by additional outcomes to take account of factors such as type of role, location, service need and risk analysis. Dementia awareness also needs to be understood in conjunction with related statutory and mandatory subjects as appropriate to role.

With an aging population, the number of people in the UK living with, or at risk of dementia is continuing to rise. In 2009, the government responded with a national dementia strategy<sup>i</sup> which included the priority to improve dementia awareness. Building on this strategy, the Prime Minister's Dementia Challenge launched in 2012 focused on areas of action to make a difference to those affected by dementia and in 2015 the Department of Health published the Prime Minister's Challenge on Dementia to 2020<sup>ii</sup> which renewed the commitment to provision of tier 1 dementia awareness training.

Dementia awareness is therefore a key priority for the entire health and care workforce. In addition to those providing clinical care or support for people living with dementia, care may be provided by support staff and other individuals who interact with those affected by dementia and who therefore need to have an awareness and understanding of the specific needs of people living with dementia and those of their carers.

### Target audience

The entire health and social care workforce (tiers 1, 2 and 3).

### Key learning outcomes

### The learner will:

a) know what is meant by the term dementia

b) be aware of the prevalence of dementia in the UK population

c) be able to recognise signs of dementia and also be aware that these signs may be associated with other conditions or circumstances

d) know what actions individuals can take to reduce their risk of dementia, or to delay onset e) know why early diagnosis of dementia is important

f) know the actions that people affected by dementia can take in order to live as well as possible after diagnosis

g) understand the importance of recognising a person with dementia as a unique individual h) be aware of the impact of dementia on individuals, families and society

g) be aware of the central role that their home, housing conditions and immediate community play in enabling a person with dementia to live well

j) be able to communicate effectively and compassionately with individuals who have dementia

k) understand reasons why a person with dementia may exhibit signs of distress and how behaviours seen in people with dementia may be a means for communicating unmet needs

I) be able to signpost individuals, families and carers to dementia advice, support and information.

<sup>&</sup>lt;sup>i</sup>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/168220/ <u>dh\_094051.pdf</u>

https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

### Relevant guidance and / or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to dementia awareness are show below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 3: Raising awareness and understanding
- Department of Health [2015] Prime Ministers Challenge 2020
- Skills for care and Skills for Health [2011], common core Principals for Supporting People with Dementia, Principle 1: Know the early signs of dementia

### Legislation

- Mental Capacity Act 2005
- Care Act 2014

# Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- SCDHSC0419 Provide advice and information to those who enquire about health and social care services
- SCDHSC0026 Support individuals to access information on services and facilities
- SFHCHS177 Advise on access to and use of services

### **Core Skills Framework**

• Clinical / Care Subject 8: Dementia awareness

### **Care Certificate Standards**

• Standard 9: Awareness of mental health, dementia and learning disabilities

### **Dementia Education Principals and Standards**

- Principal 3. Collaboration Level 1
- Principal 5. Recognition level 1

# **HEDN: A Curriculum for UK Dementia Education**

- Core Topic 1. Prevention and keeping well
- Core Topic 2. Identification and assessment of dementia
- Core Topic 3. Understanding the experience of and communicating with people with dementia

# **Regulated Qualifications Framework components**

- Dementia awareness
- Understand the process, and experience of dementia

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# Subject 2: Dementia identification, assessment and diagnosis

# Introduction

Good quality diagnosis and intervention is one of the objectives identified in the National Dementia Strategy. The Prime Minister's Challenge on Dementia 2020 renews this commitment to more people with dementia receiving a timely diagnosis and appropriate post-diagnosis support. Timely diagnosis is important as it helps people receive information, support and treatment to improve their quality of life.

The diagnosis of dementia and in particular mild dementia where the diagnosis is more complex should be carried out by a clinician with specialist skills. However, non-specialists also have an important role in being able to recognise possible symptoms of dementia, refer to specialist services and provide sympathetic and non-stigmatising support.

### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support. This subject at Tier 2 is also relevant to social care managers and leaders.

Tier 3: Key healthcare staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care.

In social care, it is recognised that the clinical learning outcomes of Tier 3 are not applicable. However, there is a recognition that social care managers, leaders and regulated professionals will in many instances be contributing alongside medical/clinical colleagues in relation to these learning outcomes.

# Key learning outcomes

Tier 2

### The learner will:

a) know the most common types of dementia in the UK and their underlying causes b) understand the signs and symptoms of dementia that would indicate the need for further assessment

c) know why early diagnosis of dementia is important and the likely outcomes if assessment and treatment is delayed

d) know the progressive nature of dementia and some of the major impairments and difficulties people may face as dementia progresses

e) understand the criteria and the process to be used to gain a diagnosis

f) be able to explain the need for an investigation of signs of dementia with sensitivity and in a way that is appropriate to the person

g) be able to appropriately refer patients to access specialist services5 and support networks

# Tier 3

Tier 2 learning outcomes plus the following

### The learner will:

a) understand the different types of dementia, the stages or variants of these diseases and their primary symptoms

b) understand how to differentiate between dementia, delirium, depression and other conditions presenting with similar symptoms

c) be able to undertake a comprehensive assessment for dementia utilising appropriate investigations and tools

d) be able to establish a differential diagnosis of dementia and the underlying disease processes, where appropriate to role

e) be aware of the potential impact of diagnostic errors

f) be able to act on the findings in partnership with people affected by dementia and the multiprofessional team

g) be aware of the experience of a person with dementia and their family and carers and be able to communicate with sensitivity about the diagnosis of dementia and related implications

h) know how to enrol the person with dementia in post-diagnosis support services and advanced care planning

i) understand the particular impact of a diagnosis for younger people with dementia and their families

j) understand the needs of people with learning disabilities and dementia

k) understand the importance of equal access to dementia assessment and diagnosis for people from diverse communities

I) be able to document assessment and diagnosis decisions

### **Relevant guidance and/or legislation**

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to dementia identification, assessment and diagnosis are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 4: Early diagnosis and support
- NICE quality standards [QS1][2010], Dementia quality standard
- Skills for Care and Skills for Health [2011]. Common Core Principals for Supporting People with Dementia, Principle 2: Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage

### Legislation

- Mental Capacity Act 2005
- Care Act [2014]
- Equality Act 2010

# Indicative mapping to relevant national standards or frameworks

# **National Occupational Standards**

- SFHCHS38 Plan assessment of an individual's health status
- SFHCHS168 Obtain a patient/client history
- SFHCHS39 Assess an individual's health status
- SFHCHS40 Establish a diagnosis of an individual's health condition
- SFHCHS41 Determine a treatment plan for an individual

• SFHCHS45 Agree courses of action following assessment to address health and wellbeing needs of individuals

• SFHCHS48 Communicate significant news to individuals

• SFHCHS84 Develop and agree care management plans with individuals diagnosed with long term conditions

# **Dementia Education Principles and Standards**

• Principle 5. Recognition Levels 2 and 3

# HEDN: A Curriculum for UK Dementia Education

• Full curriculum Topic 2. Identification and assessment of dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

• Full curriculum Topic 6. Supporting people in the early stages of dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

# **Regulated Qualifications Framework components**

- Dementia awareness
- Understand the process and experience of dementia

# Subject 3: Dementia risk reduction and prevention

### Introduction

Evidence suggests that some types of dementia are related to modifiable lifestyle factors. In particular, interventions to address vascular risk factors (e.g. smoking, poor diet, physical inactivity and alcohol) should also help to reduce the risk, progression and severity of dementia. This suggests that primary prevention in settings across the health and care sectors has a role in dementia risk reduction similar to that for other non-communicable diseases such as heart disease and stroke.

# **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

### Key learning outcomes

### Tier 2

### The learner will:

a) know the lifestyle factors that may increase the risk of developing certain types of dementia and how lifestyle changes may delay the onset and severity of certain types of dementia

b) understand motivational factors that may impact on the ability to make changes

c) be aware of the challenges to healthy living that may be experienced by different socio- economic and/or ethnic groups

d) be able to signpost sources of health promotion information and support

e) know how to effectively communicate messages about healthy living according to the abilities and needs of individuals.

### Tier 3

Tier 2 learning outcomes plus the following

### The learner will:

a) be aware of dementia risk reduction evidence-based research and national health promotion strategies

b) be able to develop and disseminate health promotion information and advice

c) be able to encourage behavioural change in individuals and organisations to promote health and well-being, reduce risk and potentially delay the onset and severity of certain types of dementia

d) understand the importance of an approach to risk reduction which challenges myths and stigma

e) be able to monitor, evaluate and improve the effectiveness of health promotion activities. **Relevant guidance and/or legislation** 

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to dementia risk reduction and prevention are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 3: Raising awareness and understanding
- Public Health England and UK Health Forum [2014], Blackfriars Consensus on promoting brain health

### Legislation

- Mental Capacity Act 2005
- Care Act [2014]

### Indicative mapping to relevant national standards or frameworks National Occupational Standards

• SFHHT2 Communicate with individuals about promoting their health and wellbeing

• SFHHT3 Enable individuals to change their behaviour to improve their own health and wellbeing

• SFHPHP13 Provide information to individuals, groups and communities about promoting health and wellbeing

• SFHPHP15 Encourage behavioural change in people and agencies to promote health and wellbeing

• SFHPHP41 Enable people to address issues related to health and wellbeing

• SFHGEN127 Assess the need for, and plan awareness raising of health and wellbeing issues

• SFHGEN128 Support the implementation, monitoring, evaluation and improvement of awareness raising around health and wellbeing issues

• SCDHSC0438 Develop and disseminate information and advice about health and social well-being

### **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 1. Prevention and keeping well Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

# Subject 4: Person-centred dementia care

### Introduction

Person-centred dementia care is about understanding and responding to the person with dementia as an individual. It involves considering the whole person, taking into account not just their health condition, but also each individual's life history, unique abilities, interests, culture, preferences and needs. It is about building relationships with people with dementia and their family carers, putting them at the heart of decision making – ensuring the person is an equal partner in their health and care.

The values associated with person-centred care include the recognition and promotion of individuality, independence, privacy, partnership, choice, dignity, respect and rights.

### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

### Key learning outcomes

#### Tier 2

### The learner will:

a) understand the principles of person-centred dementia care i.e.

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with dementia the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being

b) understand how person-centred care can provide insights into the experiences of the person with dementia and support care approaches and solutions to meet individual needs

c) understand the role of family and carers in person-centred care and support of people with dementia

d) understand how a person-centred approach can be implemented, including the use of advance planning and life story work

e) understand that a person's needs may change as the disease progresses

f) know how to adapt the physical environment to meet the changing needs of people with dementia

g) understand the significance of a person's background, culture and experiences when providing their care

h) understand the importance of clear documentation to communicate the care needs of the person with dementia

i) understand the need for a balance between healthy living, a nutritionally balanced diet and providing the opportunity for those living with dementia to enjoy the food and drink of their choice (preference or cultural etc.) but also recognising that their nutritional needs may be different from general population healthy eating / prevention messages

### Tier 3

Tier 2 learning outcomes plus the following

# The learner will:

a) understand the value of person-centred care in therapeutic relationships and communication b) understand the importance of person-centred approaches in the management and development of services

c) be able to incorporate person-centred approaches in the management and development of services

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to person-centred dementia care are shown below:

### Guidance

- Care Fit for VIPS
- NICE quality standards [QS1][2010], Dementia quality standard
- NICE Guidance [CG42][2006], Dementia: Supporting people with dementia and their carers in health and social care3
- · Open Learn: The importance of person-centred approach to nursing care
- Alzheimers Society: Person-centred care

### Legislation

- Mental Capacity Act 2005
- Human Rights Act 1998

# Indicative mapping to relevant national standards or frameworks

# **National Occupational Standards**

- SCDHSC0332: Promote individuals' positive self-esteem and identity
- SCDHSC0234: Uphold the rights of individuals
- SCDHSC0414 Assess individual preferences and needs

• SCDHSC0415 Lead the service delivery planning process to achieve outcomes for individuals

• SFHGEN111 Enable individuals, their family and friends to explore and manage change

• SFHCHS233 Contribute to the assessment of needs and the planning, evaluation and review of individualised programmes of care for individuals

# **Core Skills Frameworks**

- Clinical/Care Subject 3: Person-centred care
- Person-Centred Approaches
- · End of Life Care Subject 1: Person-centred end of life care
- Frailty Capability 3: Person-centred approaches

# **Care Certificate Standards**

· Standard 5: Work in a person-centred way

### **Dementia Education Principles and Standards**

- Principle 1. Person-Centred Dementia Care Levels 1, 2 and 3
- Principle 10. Advance Care Directives Level 1

# **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 7. Developing person centred care, assessment and care planning Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

• Full curriculum Topic 5. Equality, diversity and inclusion in dementia care Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

# **Regulated Qualifications Framework components**

- Dementia awareness
- The person centred approach to the care and support of individuals with dementia

• Understand and Implement a person centred approach to the care and support of individuals with dementia

Understand the factors that can influence communication and interaction with individuals who have dementia

- · Understand equality, diversity and inclusion in dementia care
- · Equality, diversity, and inclusion in dementia care practice
- Understand and enable interaction and communication with individuals with dementia
- · Approaches to enable rights and choices for individuals with dementia whilst minimising risks
- · Understand the process and experience of dementia
- · Understand and meet the nutritional requirements of individuals with dementia

• Understand the administration of medication to individuals with dementia using a person centred approach

- · Understand the diversity of individuals with dementia and the importance of inclusion
- · Understand and enable interaction and communication with individuals who have dementia
- · Equality, diversity and inclusion in dementia care practice
- Lead and manage practice in dementia care

# Subject 5: Communication, interaction and behaviour in dementia care

### Introduction

People with dementia face particular challenges around communication. Dementia may affect a person's ability to understand and use language – their language skills may vary from day to day and become increasingly difficult as their condition progresses.

Effective communication will depend upon the needs and abilities of each individual. Non-verbal communication may become increasing important as verbal abilities decline. Health and care professionals must be aware of the importance of their non-verbal communication such as body language, facial expression and touch.

The behaviour of a person with dementia (including challenging and distressed behaviour) is also an important form of communication – possibly indicating their feelings and perceptions. Recognising this can be a key component of effective communication.

### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

### Key learning outcomes

Tier 2

### The learner will:

a) understand the importance of effective communication in dementia care

b) understand the impact of memory and language difficulties on communication c) be able to demonstrate active listening skills

d) be able to gain a person's attention before asking a question or beginning a task with them e) understand the importance of speaking clearly, calmly and with patience

f) know how to adapt the environment to minimise sensory difficulties experienced by an individual with dementia

g) know the importance of ensuring that individuals have any required support (e.g. dentures, spectacles, hearing aids) to enable successful communication and the role that a clean, pain-free mouth plays in speech

h) know how life story information may enable or support more effective communication

i) understand the importance of effective communication with family and carers and the expertise that they may be able to offer to support effective communication with the person with dementia

j) be able to adapt communication techniques according to the different abilities and preferences of people with dementia

k) be aware of the importance of non-verbal communication e.g. body language, visual images and the appropriate use of touch

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I) understand that the behaviour of a person with dementia is a form of communication and how behaviours seen in people with dementia may be a means for communicating unmet needs

m) understand how a person's feelings and perception may affect their behaviour n) understand how the behaviour of others might affect a person with dementia o) understand common causes of distressed behaviour by people with dementia

p) be able to recognise distressed behaviour and provide a range of responses to comfort or reassure the person with dementia.

### Tier 3

Tier 2 learning outcomes plus the following

### The learner will:

a) be able to contribute to the development of practices and services that meet the communication needs of people with dementia

b) be able to promote effective communication in a health and care environment.

### Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to communication, interaction and behaviour in dementia care are shown below:

### Guidance

- The VERA Framework [Blackall et al, 2011]
- Skills for Care and Skills for Health [2011], Common Core Principals for Supporting People with Dementia, Principal 3: Communicate sensitively to support meaningful interaction
- Alzheimer's Society [2012], Factsheet: Communicating
- Skills for Health [2015], Stand By Me [Person-centred communication in dementia care]

### Legislation

- Mental Capacity Act 2005
- Care Act [2014]

# Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- SFHGEN97: Communicate effectively in a healthcare environment
- SFHGEN98: Promote effective communication in a healthcare environment
- SCDHSC0031: Promote effective communication
- · SCDHSC0369 Support individuals with specific communication needs

### **Core Skills Frameworks**

- Clinical/Care Subject 4: Communication
- Person-Centred Approaches
- End of Life Care Subject 2: Communication in end of life care
- Frailty Capability 4: Communication

# **Care Certificate Standards**

Standard 6: Communication

### **Dementia Education Principles and Standards**

• Principle 2. Communication Levels 1, 2 and 3

# **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 3. Understanding the experience of and communicating with people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

### **Regulated Qualifications Framework components**

• Understand and Implement a person-centred approach to the care and support of individuals with dementia

• Understand the factors that can influence communication and interaction with individuals who have dementia

· Understand and enable interaction and communication with individuals with dementia

• Understand the administration of medication to individuals with dementia using a person-centred approach

- Understand the role of communication and interactions with individuals who have dementia
- · Understand the diversity of individuals with dementia and the importance of inclusion
- Understand and enable interaction and communication with individuals who have dementia

# Subject 6: Health and well-being in dementia care

### Introduction

This is about helping people with dementia to maintain and optimise their physical health and psychological well-being. It includes recognising and responding to physical needs such as food, drink, physical activity, hygiene, pain relief and psychological needs associated with delirium, anxiety and depression. It also requires knowledge of a range of potential interventions including awareness of the appropriate role of medication and how to enable and support psycho-social and therapeutic interventions. The importance of food and drink is based on the emerging evidence base that links a reduction in mealtime eating and behavioural abilities with decreased nutrition, hydration and reductions in quality of life. Conversely, socialisation and other person-centred mealtime interventions can enhance the pleasure of eating and mealtime abilities and lead to improved nutrition and hydration.

### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support. This subject at Tier 2 is also relevant to social care managers and leaders.

Tier 3: Key healthcare staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care.

In social care, it is recognised that the clinical learning outcomes of Tier 3 are not applicable. However, there is a recognition that social care managers, leaders and regulated professionals will in many instances be contributing alongside medical/clinical colleagues in relation to these learning outcomes.

### Key learning outcomes

Tier 2

### The learner will:

a) understand the importance for individuals with dementia to maintain good physical, mental and oral health through food, drink, exercise and a healthy life style that includes social engagement

b) be aware of anticipating an individual's health needs e.g. to prevent fatigue, falls, dehydration and hunger

c) know the action to take in response to identification of fatigue and falls

d) know how to take action in response to dehydration and hunger (including unplanned weight-loss), how to improve the provision of good nutrition and hydration through monitoring food and drink intake using appropriate tools and understand the factors that influence mealtimes to provide a positive mealtime experience

e) know where to find evidence-based information and resources and when to refer for more specialist advice from a registered dietitian/registered nutritionist on nutrition or other health care professional e.g. speech and language therapist for textured modified foods

f) know how to recognise and manage pain in people with dementia

g) be able to support an individual in maintaining personal appearance, cleanliness, and good oral hygiene

- h) be aware of the impact of delirium, depression and social stressors
- i) understand triggers and responses to stressed or distressed behaviours

j) understand the role of family and carers in supporting the health and well-being of people with dementia

k) be aware of the benefits and limitations of medication to manage behavioural and psychological issues including associated risks

I) be able to support individuals in undertaking psycho-social interventions including validation, counselling, reminiscence and life story work

m) be aware of the role of therapeutic work including complementary therapies and sensory stimulation

n) know how to support people with dementia to access local services and referral pathways including voluntary and community services which would promote their physical, mental and oral health.

### Tier 3

Tier 2 learning outcomes plus the following

### The learner will:

a) understand the signs of dementia, depression and delirium and appropriate responses and treatment options

b) understand the complexity of ageing and co-morbidity in dementia

c) understand the benefits and implications of pharmacological interventions that may enhance memory

d) understand the evidence for the effectiveness of different psycho-social approaches in different situations

e) understand the principles and key aspects of psycho-social approaches used to enhance the wellbeing of people with dementia

f) be aware of new and emerging knowledge of psycho-social approaches that can be used to enhance the well-being of people with dementia.

A number of interventions have a proven evidence based to support people living with dementia. It is important to stress that people delivering these need an appropriate level of qualification(s), training and supervision to deliver these interventions:

• Cognitive Stimulation Therapy (CST)

• Cognitive Behaviour Therapy (CBT) for people living with dementia and their carers who also have depression / anxiety. CBT is a highly skilled psychological therapy regulated in the UK by the BABCP (British Association of Behavioural and Cognitive Therapists).

• STrAtegies for RelaTives (START) - a programme that aims to reduce depression and anxiety in family carers.

• Systemic family therapy for people with dementia and their families. Family Therapy is a highly skilled psychological therapy which is regulated by the Association of Family Therapists which in turn is allied to the United Kingdom Council for Psychotherapy (UKCP).

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to holistic health in dementia care are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 5: Living well with dementia
- Nice quality standard [QS30][2013], Quality standard for supporting people to live well with dementia
- Skills for Care and Skills for Health [2011], Common Core Principals for Supporting People with Dementia, Principal 4: Promote independence and encourage activity.

### Legislation

- Care Act [2014]
- Equality Act 2010

### Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- SCDHSC0212 Support individuals during therapy sessions
- SCDHSC0213 Provide food and drink to promote individuals' health and well being
- SCDHSC0214 Support individuals to eat and drink
- SCDHSC0216 Help address the physical comfort needs of individuals
- SCDHSC0218 Support individuals with their personal care needs
- SCDHSC0219 Support individuals to manage continence
- SCDHSC0025 Contribute to implementation of care or support plan activities
- SCDHSC3112 Support individuals to manage their own health and social well-being
- SCDHSC0393 Promote participation in agreed therapeutic group activities
- SFHGEN105 Enable individuals to maintain their personal hygiene and appearance
- SFHGEN107 Enable individuals and families to put informed choices for optimising their health and wellbeing into action
- SFHCHS62 Provide interventions to individuals with long term conditions 39
- SFHCHS68 Support individuals with long term conditions to manage their nutrition
- SFHCMA4 Plan, implement, monitor and review therapeutic interventions with individuals who have a long term condition and their carers

• SFHCMC3 Enable individuals with long term conditions to make informed choices concerning their health and wellbeing

### **Core Skills Frameworks**

- Clinical/Care Subject 7: Fluids and nutrition
- Frailty Capability 9: Physical and mental health and wellbeing

### **Care Certificate Standards**

Standard 8: Fluids and nutrition

### **Dementia Education Principles and Standards**

• Principle 7. Essentials of Physical Care Levels 1, 2 and 3.

### HEDN: A Curriculum for UK Dementia Education

- Full curriculum Topic 8. Holistic health for people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)
- Full curriculum Topic 9. Supporting the daily life of people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)
- Full curriculum Topic 11. Psycho-social approaches for people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

### **Regulated Qualifications Framework components**

- The person-centred approach to the care and support of individuals with dementia
- Understand and meet the nutritional requirements of individuals with dementia
- Understand the administration of medication to individuals with dementia using a person-centred approach
- · Understand the role of communication and interactions with individuals who have dementia
- Understand the diversity of individuals with dementia and the importance of inclusion
- Understand and enable interaction and communication with individuals who have dementia

# Subject 7: Pharmacological interventions in dementia care

# Introduction

On occasions, medication may be prescribed for people with dementia, both to address the symptoms of dementia and related health needs they may experience. In such cases, the prescription of medication must be in accordance with current guidance and with an understanding of any contra-indications and related ethical issues. Medication must also be administered safely and appropriately.

The Prime Minister's Challenge on Dementia (2015) particularly highlights the issue of inappropriate use of antipsychotic medication, normally in response to behavioural and psychological symptoms of dementia and notes that antipsychotic drugs "should only be prescribed to people with dementia in exceptional circumstances and if prescribed, this should be reviewed on a regular basis".

# **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key healthcare staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care.

In social care, it is recognised that the clinical learning outcomes of Tier 3 are not applicable. However, there is a recognition that social care managers, leaders and regulated professionals will in many instances be contributing alongside medical/clinical colleagues in relation to these learning outcomes.

### Key learning outcomes

Tier 2

### The learner will:

a) know the most common medications used to treat the symptoms of dementia

b) know the main risks and benefits of using anti-psychotics, anti-depressants, anxiolytics, anticonvulsants and cognitive enhancers and be aware of the impact drugs may have on daily living, including common side effects such as taste disturbances and a dry mouth

c) be aware of issues around polypharmacy for people with dementia

d) understand the importance of recording and reporting side effects and/or adverse reactions to medication

e) be able to administer and review medication safely and appropriately in consultation with people affected by dementia.

### Tier 3

Tier 2 learning outcomes plus the following

# The learner will:

a) understand the range of cognitive enhancers, what they do, criteria for eligibility and sources of guidance

b) understand processes for assessing and prescribing cognitive enhancers

c) understand the range of drugs to manage behavioural and psychological symptoms of dementia and when such drugs should or should not be used

d) understand the ethical issues around drug treatments in the care of people living with dementia

e) understand contra-indications for prescribing anxiolytics and anti-psychotic medication

f) understand the range of medication to address common physical health problems of people with dementia, including the risks associated with how these drugs may interact with cognitive enhancers and drugs prescribed to address behavioural and psychological issues

g) understand the importance of regular reviews of prescribed medication

h) understand how to assess pain experienced by people with dementia and prescribing practice to address pain effectively

i) be aware of new and emerging knowledge of pharmacological interventions that can be used to enhance the well-being of people with dementia.

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to pharmacological interventions in dementia care are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 5: Living well with dementia / section 31 & 32
- Department of Health [2015] Prime Ministers Challenge on Dementia 2020
- Minister of State for Care Services [2009], The use of antipsychotic medication for people with dementia: Time for action
- Nice Guidance [CG42][2006], Dementia: Supporting people with dementia and their carers in health and social care

### Legislation

- Mental Capacity Act 2005
- Equality Act 2010

# Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- SFHCHS2 Assist in the administration of medication
- SFHCHS3 Administer medication to individuals
- SFHCMA7 Prescribe medication for individuals with a long-term condition
- SFHAH12 Enable individuals to take their medication as prescribed
- SCDHSC3122 Support individuals to use medication in social care settings

### **Core Skills Framework**

• Frailty Capability 10: Managing medication

# **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 10. Pharmacology relating to the needs of people with dementia Tier 2 (Level 5) and Tier 3 (Level 6/7)

# **Regulated Qualifications Framework components**

• Understand the administration of medication to individuals with dementia using a person centred approach

End of Life and dementia care

# Subject 8: Living well with dementia and promoting independence

# Introduction

People with dementia should be encouraged to maintain the activities they enjoy and continue to be active. This may include supporting people to adapt their homes to enable them to keep safe and promote their independence. People can also be supported to avoid isolation by maintaining a social life and involvement in their local community.

# **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

### Key learning outcomes

Tier 2

# The learner will:

a) understand the importance of physical activity (including access to outside space) in maintaining a person's independence and abilities

b) be able to support individuals to meet their daily living needs

c) be able to support individuals to continue their interests, social life and community involvement and know why this is important

d) know about community initiatives such as the development of dementia friendly environments

e) understand the needs of individuals for day to day closeness with others e.g. sharing thoughts and feelings

f) understand how to recognise and respond to cultural, spiritual and sexual needs of people with dementia

g) understand the role of family and carers in enabling people with dementia to live well h) understand how activities can be adapted to suit an individual's changing needs

i) be able to incorporate assistive technology to support self-care and meaningful activity j) be able to develop strategies to reduce the struggle with unfamiliar environments

k) be aware of ways to adapt the physical environment to promote independence, privacy, orientation and safety (e.g. to reduce risk of falls)

I) know about perceptual distortions that may occur in dementia and how the impact of such distortion can be minimised by changes to the environment

m) understand the importance of food-related activities to stimulate appetite and support engagement and independence in food preparation, eating and drinking.

# Tier 3

Tier 2 learning outcomes plus the following

### The learner will:

a) be able to contribute to the development of practices and services that meet the individual needs of people with dementia

b) understand the principles, processes and options for self-directed support

c) be able to support the person with dementia and their family to access self-directed support if desired

d) be able to provide dementia specific advice and guidance on adapting the physical and social environment to ensure physical safety and emotional security

e) know of housing sectors, providers and services and be able to work in partnership with appropriate providers to deliver required outcomes

f) be able to lead on the introduction of assistive technology to support self-care and meaningful activity.

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to living well with dementia and promoting independence are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A National Dementia Strategy, Chapter 5: Living well with dementia
- NICE quality standard [QS30][2013], Quality standard for supporting people to live well with dementia
- Skills for Care and Skills for Health [2011], Common Core Principals for Supporting People with Dementia, Principal 4: promote independence and encourage activity
- Alzheimer's Society [2013] . The dementia guide: Living well after diagnosis

### Legislation

- Mental capacity Act 2005
- Equality Act 2010

# Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- · SCDHSC210 Support individuals to participate in recreational activities
- SCDHSC0027 Support individuals in their daily living
- SCDHSC345 Support individuals to manage their financial affairs
- SCDHSC0346 Support individuals to manage direct payments
- SCDHSC0350 Support the spiritual well-being of individuals
- SCDHSC0370 Support the use of technological aids to promote independence
- SCDHSC0393 Promote participation in agreed therapeutic group activities
- SCDHSC0450 Develop risk management plans to promote independence in daily living
- SFHCHS153 Enable individual expression using creative arts therapies
- SFHCHS239 Enable individuals to use assistive devices and assistive technology
- SFHGEN75 Collaborate in the assessment of the need for, and the provision of, environmental and social support in the community
- SFHMH68.2013 Co-produce action plans which assist stakeholders in improving environments and practices to promote mental health
- SFHMH66.2013 Assess how environments and practices can be maintained and improved to promote mental health

### **Core Skills Framework**

• Frailty Capability 8: Living well with frailty, promoting independence and community skills

# **HEDN: A Curriculum for UK Dementia Education**

- Full curriculum Topic 9. Supporting the daily life of people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)
- Full curriculum Topic 8. Holistic health for people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

### **Regulated Qualifications Framework components**

- Approaches to enable rights and choices for individuals with dementia whilst minimising risks
- · Enable rights and choices of individuals with dementia whilst minimising risks

# Subject 9: Families and carers as partners in dementia care

# Introduction

The majority of care for people with dementia is undertaken by their family carers – however, many family carers report that this results in high levels of stress, depressive symptoms and social isolation. Typically, family carers will want to continue in their caring role, but it is important that they are supported to maintain their own health and well-being as well as be given the support to care for the person with dementia. Increasingly, family carers and health and care professionals are seen as partners in the care process.

The Prime Minister's Challenge on Dementia includes the aspiration that carers of people with dementia "be made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring"

### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

# Key learning outcomes

Tier 2

### The learner will:

a) understand the significance of family, carers and social networks in planning and providing care

b) understand the importance of developing partnerships with family members and carers

c) understand the impact that caring for a person with dementia in the family may have on relationships

d) understand the importance of recognising and assessing a carer's own needs, including respite

e) be aware of the complexity and diversity in family arrangements

f) be aware that the needs of carers and the person with dementia may not always be the same g) understand potential socio-cultural differences in the perception of the care giving role

h) be aware of the impact on younger carers and their concerns

i) be able to communicate compassionately, effectively and in a timely manner with care partners

j) be able to support family carers to access and use information and local support networks including housing sectors, providers and services

k) be able to support family carers in considering options and making decisions

I) be able to gather information about a person's history and preferences from family carers.

### Tier 3

Tier 2 learning outcomes plus the following

# The learner will:

a) be able to contribute to the development of practices and services that meet the needs of families and carers

b) understand methods to assess a carer's psychological and practical needs and the relevant support available

c) understand the potential for dilemmas arising where there are differing needs between people with dementia and their carers

d) understand the role of personalisation in care e.g. the impact of access to personal budgets f) understand legislation relevant to carers and carers rights

g) be able to signpost carers for further support around legal issues (e.g. lasting power of attorney and legal issues connected with housing such as tenancy rights).

### Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to families and carers as partners in dementia care are shown below:

### Guidance

- Department of Health [2009], Living Well with Dementia: A national Dementia Strategy, Objective 7: Implementing the Carers' Strategy for people with dementia
- Department of Health [2015] prime Minister's Challenge on Dementia 2020
- NICE quality standard [QS1][2010], Dementia quality standard
- NICE and SCIE [2006], Dementia: Supporting people with dementia and their carers in health and social care
- Skills for Care and Skills for Health [2011], Common Core Principals for Supporting People with Dementia, Principal 6: Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice
- Department of health [2010], Recognised, valued and supported: Next steps for Carers Strategy
- Department of Health [2014], Care and Support Statutory Guidance: Issued under the Care
  Act 2014
- Department of Health [2014], Care Act factsheets, Factsheet 8: The law for carers
- Carers Trust [2013], The Triangle of Care: carers Included: A Guide to Best Practice for Dementia Care

# Legislation

- Care Act [2014]
- Mental Capacity Act 2005

### Indicative mapping to relevant national standards or frameworks

### **National Occupational Standards**

- SCDHSC0227 Contribute to working in partnership with carers
- SCDHSC0387 Work in partnership with carers to support individuals
- SCDHSC0390 Support families in maintaining relationships in their wider social structures and environments
- SCDHSC0426 Empower families, carers and others to support individuals
- SCDHSC0427 Assess the needs of carers and families
- SCDHSC0428 Lead the development of programmes of support for carers and families
- SFHGEN20 Enable carers to support individuals
- SFHGEN103 Establish, sustain and disengage from relationships with the families of individuals with specific health needs
- SFHCHS58 Provide information and support to carers of individuals with long term conditions
- SFHCHDHN3 Enable carers to access and assess support networks and respite services
- SFHCMC5 Build a partnership between the team, patients and carers

# **Core Skills Framework**

• Frailty Capability 5: Families and carers as partners in care 52

# HEDN: A Curriculum for UK Dementia Education

• Full curriculum Topic 4. Creating effective partnerships with carers & families Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

### **Regulated Qualifications Framework components**

- The person-centred approach to the care and support of individuals with dementia
- Understand and Implement a person-centred approach to the care and support of individuals with dementia
- · Approaches to enable rights and choices for individuals with dementia whilst minimising risks
- · Understand the process and experience of dementia
- · Understand and meet the nutritional requirements of individuals with dementia

- Enable rights and choices of individuals with dementia whilst minimising risks
- Understand the diversity of individuals with dementia and the importance of inclusion
- End of Life and dementia care
- Lead and manage practice in dementia care

# Subject 10: Equality diversity and inclusion in dementia care

## Introduction

Dementia will affect people from all cultural and ethnic backgrounds. Issues of cultural and ethnic diversity may have an impact on how people experience dementia, including the acceptance of the condition within their family or community.

Dementia is generally regarded as a condition associated with old age. However, there are a significant number of people with younger onset dementia and they are likely to have specific needs and concerns.

In addition, many of the characteristics covered by the Equality Act and related to the wider determinants of health can have a significant bearing on experiences of dementia, including but not limited to an individual's sexuality, disabilities, gender, geographical location etc.

#### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

#### Key learning outcomes

Tier 2

## The learner will:

a) be aware of cultural diversity and equality issues, and how they may impact on people with dementia

b) be able to adapt assessment and care planning taking account of equality issues (e.g. cultural diversity, disabilities, gender and sexual orientation)

c) understand diversity in family arrangements and the local community

d) be aware of the stigma, myths and stereotypes associated with dementia e) be aware of the prevalence and impact of younger onset dementia

f) be aware of legislation to support carers, including young carers g) understand the additional concerns of younger carers

h) be aware of the impact of dementia on people with learning disabilities

i) be aware of socio-cultural differences in the perception of the care giving role e.g. based on gender

j) be able to actively challenge any discriminatory practice that may compromise a person's right to dignity, respect and safety.

# Tier 3

Tier 2 learning outcomes plus the following

## The learner will:

a) understand the impact that discrimination and stigma may have on the life of the person with dementia, their family and carers

b) be able to lead practice and an organisational culture that values and respects the diversity of individuals

c) understand legislation relevant to equality, diversity and human rights.

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to equality diversity and inclusion in dementia care are shown below:

# Guidance

- Department of Health [2014], Care and Support Statutory Guidance: Issued under the care Act 2014
- Department of Health [2011], national Dementia Strategy: Equalities Action Plan

# Legislation

- Care Act [2014]
- Equality Act 2010
- Human Rights Act 1998

# Indicative mapping to relevant national standards or frameworks

## **National Occupational Standards**

- SFHSS01 Foster people's equality, diversity and rights
- SCDHSC0234 Uphold the rights of individuals
- SCDHSC3111 Promote the rights and diversity of individuals

• SCDHSC0452 Lead practice that promotes the rights, responsibilities, equality and diversity of individuals

# **Core Skills Framework**

• Statutory/Mandatory Subject 1: Equality, diversity and human rights

# **Care Certificate Standards**

• Standard 4: Equality and diversity

# **Dementia Education Principles and Standards**

• Principle 1. Cultural Diversity Levels 1, 2 and 3

# **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 5. Equality, diversity and inclusion in dementia care Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

## **Regulated Qualifications Framework components**

- · Understand equality, diversity and inclusion in dementia care
- Equality, diversity, and inclusion in dementia care practice
- Understand the diversity of individuals with dementia and the importance of inclusion
- Equality, diversity and inclusion in dementia care practice

# Subject 11: Law, ethics and safeguarding in dementia care

# Introduction

Staff working with people living with dementia must be fully aware of their duty of care, particularly where they may be required to make decisions in situations where people are unable to make decisions for themselves. Duty of care is about always acting in the best interests of others and not acting or failing to act in ways that result in harm. In dementia care, this is likely to include ethical issues such as the need to balance a person's safety with their need for independence, deciding the best interests for the person with dementia (e.g. when making decisions about consent to treatment) and recognising that the needs of the person with dementia may sometimes conflict with the needs of others, especially carers.

People with dementia may also be vulnerable to situations where they could suffer neglect, harm or exploitation. In recent years a number of high profile cases have highlighted distressing examples where there have been failings in the duty of care as documented in the Francis Report (2013) and the Cavendish Review (2013). These cases serve to highlight the vital importance of raising concerns and acting on them before it is too late. Therefore, health and care staff must be able to recognise and address any areas of concern and have the confidence to speak out when required.

# **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

## Key learning outcomes

Tier 2

## The learner will:

a) understand how duty of care contributes to safe practice and facilitates decision-making

b) be aware of dilemmas that may arise between the duty of care and an individual's rights and carers wishes

c) be able to communicate effectively about proposed treatment or care to enable people with dementia to make informed choices as far as practicable

d) understand the protocols regarding consent to treatment or care for people who may lack mental capacity

e) understand how 'best interests' decisions may need to be made for those lacking capacity f) know how advance directives can be used to provide information about the wishes of an individual

g) be able to recognise a range of factors which may indicate neglect, abusive or exploitative practice

h) know what to do if neglect, abusive or exploitative practice is suspected, including how to raise concerns within local safeguarding or whistle blowing procedures

i) be aware of key legislation relevant to mental capacity, deprivation of liberty, equality and human rights.

## Tier 3

Tier 2 learning outcomes plus the following

# The learner will:

a) understand the options available when informed consent may be compromised b) be able to respond to safeguarding alerts / referrals

c) know the evidence-based approaches and techniques to assess neglect or abuse

d) understand the roles and responsibilities of the different agencies involved in investigating allegations of neglect or abuse

e) understand the importance of sharing safeguarding information with the relevant agencies f) know the actions to take if there are barriers to alerting the relevant agencies

g) understand key legislation relevant to mental capacity, deprivation of liberty, equality and human rights.

## Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to law, ethics and safeguarding in dementia care are shown below:

## Guidance

- Department of Health [2009], Reference guide to consent for examination or treatment
- Department of Health [2014], Care and Support statutory Guidance: Issued under the care Act 2014
- Nuffield Council on Bioethics [2009], Dementia ethical issues
- NICE quality standard [QS1][2010], Dementia quality standard
- Alzheimer's Society [2014], Fact Sheet: Deprivation of Liberty Safeguards [DoLs]

## Legislation

- Care Act [2014]
- Data Protection Act 1998
- Equality Act 2010
- Human Rights Act 1998
- Mental Capacity act 2005
- Safeguarding Vulnerable Groups Act 2006

# Indicative mapping to relevant national standards or frameworks

#### **National Occupational Standards**

- SCDHSC0024: Support the safeguarding of individuals
- SCDHSC0035: Promote the safeguarding of individuals
- SCDHSC0045: Lead practice that promotes the safeguarding of individuals
- · SCDLMCB1 Lead and manage practice that promotes the safeguarding of individuals
- SCDHSC0234 Uphold the rights of individuals
- SCDHSC0395 Contribute to addressing situations where there is risk of danger, harm or abuse
- SCDHSC0430 Lead practice to reduce and prevent the risk of danger, harm and abuse
- SCDHSC431 Support individuals where abuse has been disclosed
- SFHCHS167: Obtain valid consent or authorisation

• SFHCHS229 Assess individuals' needs and circumstances and evaluate the risk of abuse, failure to protect and harm to self and others

• SFHOP10 Create an environment to protect older people from abuse

#### **Core Skills Frameworks**

- Statutory/Mandatory Subject 8: Safeguarding Adults
- Clinical/Care Subject 2: Duty of care / Subject 5: Consent
- · End of Life Care Subject 12: Law, ethics and safeguarding
- Frailty Capability 12: Law, ethics and safeguarding

## **Care Certificate Standards**

- Standard 3: Duty of Care
- Standard 10: Safeguarding Adults

## **Dementia Education Principles and Standards**

- Principle 1. Ethics Levels 1, 2 and 3
- Principle 10. Advance Care Directives Levels 2 and 3

## **HEDN: A Curriculum for UK Dementia Education**

- Full curriculum Topic 13. Understanding legal aspects of working with people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)
- Full curriculum Topic 14. Understanding ethical issues in caring for people with dementia Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

# **Regulated Qualifications Framework components**

- Approaches to enable rights and choices for individuals with dementia whilst minimising risks
- Enable rights and choices of individuals with dementia whilst minimising risks
- Understand the diversity of individuals with dementia and the importance of inclusion

# Subject 12: End of life dementia care

# Introduction

At the end of life for a person with dementia it is important to understand the use and implications of advanced care planning. Symptoms associated with end of life must be effectively managed with care and compassion. In particular, signs of pain must be identified

(even if not clearly expressed) and pain relief provided. Focus should also be on the individual's hydration needs and maintaining a comfortable mouth whilst recognising the decrease in appetite. It is also important to acknowledge the needs of bereaved family and carers.

The Prime Minister's Challenge on Dementia includes the aspiration that all people with dementia and their carers receive "co-ordinated, compassionate and person-centred care towards and at the end of life including access to high quality palliative care from health and social care staff trained in dementia and end of life, as well as bereavement support for carers"

#### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

## Key learning outcomes

Tier 2

## The learner will:

a) understand the use of end of life care pathways and individualised care plans taking into account psycho-social needs

b) understand how advanced decisions/directives and best interest decision will affect caring activities

c) know how to recognise and manage pain and address the broader physical needs (e.g. hydration, reduced appetite) in people with advanced dementia

d) be able to identify symptoms associated with end of life and how these symptoms can be managed with care and compassion

e) be aware of concerns and needs affecting younger people at the end of life

f) be aware of the needs of bereaved families and friends including the potential for conflicting emotions

g) be able to support family and friends to celebrate the life of the deceased person

h) be aware of cultural and religious differences associated with death, care of the dying and the deceased person.

# Tier 3

Tier 2 learning outcomes plus the following

# The learner will:

a) be able to contribute to the development of practices and services that meet the end of life needs of people with dementia

b) understand the processes involved in deciding when a person with dementia is deemed to be at end of life

c) be able to provide dementia specific advice and guidance on end of life care.

# Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to end of life dementia care are shown below:

# Guidance

- Department of Health [2209], Living Well with Dementia: A National Dementia Stratergy, Objective 12: Improved end of life care for people with dementia
- Department of Health [2015] Prime Ministers Challenge on Dementia 2020
- NICE Guidance [CG42][2006], D3ementia: Supporting people with dementia and their carers in health and social care
- NICE quality standard [QS1] [2010], Dementia quality standard

## Legislation

- Mental capacity Act 2005
- Equality Act 2010

# Indicative mapping to relevant national standards or frameworks

#### **National Occupational Standards**

- SCDHSC0384 Support individuals through bereavement
- SCDHSC0385 Support individuals at the end of life

## **Core Skills Framework**

• End of Life Care

# **Dementia Education Principles and Standards**

• Principle 6. End of Life Care Levels 1, 2 and 3

# HEDN: A Curriculum for UK Dementia Education

• Full curriculum Topic 15. End of life palliative care Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

# **Regulated Qualifications Framework components**

- Understand the diversity of individuals with dementia and the importance of inclusion
- Equality, diversity and inclusion in dementia care practice
- End of Life and dementia care

# Subject 13: Research and evidence-based practice in dementia care

# Introduction

The continuing development of dementia services and treatment requires on-going research and development of evidence-based practice. This includes evaluating the outcomes and impact of services and interventions. When people affected by dementia participate in research activities, this must be handled with due regard for the ethical issues involved.

The Prime Minister's Challenge on Dementia (2015) notes that "boosting research in dementia care will also require more of the nurses, allied health, social work and other care professionals who lead and deliver care, being trained to become researchers, able to lead research on issues that matter most to patients and carers, and to deliver results into clinical practice".

#### **Target audience**

Tier 2: Health and social care staff who regularly work with people living with dementia including staff providing direct care and support.

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

## Key learning outcomes

Tier 2

#### The learner will:

- a) understand the difference between service evaluation and research
- b) be able to participate in service evaluation and research in the workplace
- c) understand how people affected by dementia may be involved in service evaluation and research.

#### Tier 3

Tier 2 learning outcomes plus the following

#### The learner will:

a) understand systematic research methods to facilitate evidence-based practice

b) understand the range of evidence that informs decision-making, care practice and service delivery

c) understand approaches to evaluating services and measuring impact, including the use of outcomes reported by people affected by dementia

d) understand the ethical issues related to conducting research with people who have a cognitive impairment

e) be able to disseminate research findings clearly and accurately in written reports or verbal presentations

f) understand the importance of continuing professional development to ensure the methods used are robust, valid and reliable.

## Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to research in dementia care are shown below:

#### Guidance

• Department of Health (2009), Living Well with Dementia: A National Dementia Strategy, Objective 17: A clear picture of research evidence and needs

#### Indicative mapping to relevant national standards or frameworks

#### **National Occupational Standards**

- SFHR&D8 Conduct investigations in selected research and development topics
- SFHR&D9 Collate and analyse data relating to research
- SFHR&D10 Interpret results of research and development activities
- SFHR&D11 Record conclusions and recommendations of research and development activities
- SFHR&D12 Present findings of research and development activities in written form
- SFHR&D13 Present findings of research and development activities orally
- SFHR&D14 Translate research and development findings into practice

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• SFHR&D15 Evaluate and report on the application of research and development findings within practice

## **Core Skills Frameworks**

• End of Life Care Subject 14: Improving quality in end of life care through policy, evidence and reflective practice

• Frailty Capability 13: Research and evidence-based practice

# **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 17. Research, policy and service development in dementia care Tier 2 (Level 5/6) and Tier 3 (Level 6/7)

## **Regulated Qualifications Framework components**

· Lead and manage practice in dementia care

# Subject 14: Leadership in transforming dementia care

# Introduction

Leaders and senior managers have a responsibility to provide direction, disseminate best practice and to motivate and support staff in meeting their objectives. This requires an understanding of the environment in which the organisation operates (e.g. national dementia strategy and policies) and an understanding of current research and developments in dementia care and treatment. Leaders can also influence the culture of their workplace regarding desired attitudes and ways of working (such as promoting person-centred approaches to care).

As well as supporting staff in their own organisation, leaders will be required to work collaboratively to deliver integrated services as part of a multi-agency team.

# **Target audience**

Tier 3: Key staff (experts) who regularly work with people living with dementia and who provide leadership in transforming care including social care managers and leaders.

# Key learning outcomes

#### The learner will:

a) understand the key drivers and policies which influence national dementia strategy and service development

b) be aware of evidence-based research, innovations and developments in dementia interventions and care

c) be able to disseminate and promote new and evidence-based practice and to challenge poor practice

d) be able to plan care to promote the use of appropriate, specific, evidence based interventions e) understand the importance of demonstrating leadership in delivering compassionate person-centred care

f) understand the importance of quality assurance and service improvement

g) know how to ensure team members are trained and supported to meet the needs of people with dementia

h) understand the importance of collaborative working in the provision of support, care and services for people with dementia, their families and carers

i) understand the roles and responsibilities of different agencies involved in dementia care

j) understand the principles of equality and diversity for access to, and delivery of services

## Relevant guidance and/or legislation

Sources of further guidance are shown in Appendix 1. Examples of national guidance or legislation with specific relevance to leadership in transforming dementia care are shown below:

# Guidance

• Skills for care and Skills for Health [2011], Common Core Principals for Supporting People with Dementia, Principal 7: Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia and Principle 8: Work as part of a multi-agency team to support the person with dementia.

# Indicative mapping to relevant national standards or frameworks

## **National Occupational Standards**

- SFHGEN13 Synthesise new knowledge into the development of your own practice
- SFHGEN126 Monitor, evaluate and improve inter-agency services for addressing health and wellbeing needs
- SCDLMCA2 Lead and manage change within care services
- SCDHSC0439 Contribute to the development of organisational policy and practice
- SCDHSC0433 Develop joint working arrangements for health and social care services
- SCDLMCB3 Lead and manage the provision of care services that deals effectively with transitions and significant life events
- CFAM&LBA2 Provide leadership in your area of responsibility

## **Core Skills Frameworks**

- End of Life Care Subject 13: Leading end of life care services and organisations
- Frailty Capability 14: Leadership in transforming services

# **Dementia Education Principles and Standards**

• Principle 3. Collaboration Levels 1 and 2

## **HEDN: A Curriculum for UK Dementia Education**

• Full curriculum Topic 12. Key professional abilities and collaborative working Tier 3 (Levels 6/7)

## **Regulated Qualifications Framework components**

Lead and manage practice in dementia care

## Appendix 1: Sources of further guidance and information

The following are resources of further guidance and information. Click on the links below to access the relevant web sites:

https://www.ageuk.org.uk/

https://www.alzheimers.org.uk/

https://www.alzheimersresearchuk.org/our-research/what-we-do/

https://www.alz.co.uk/

http://www.bild.org.uk/

https://www.carefitforvips.co.uk/#vips

https://www.carersuk.org/

https://www.crisiscareconcordat.org.uk/about/

https://www.dementiaaction.org.uk/

https://www.dementiacarer.net/

https://dementiapartnerships.com/

https://www.dementiauk.org/

https://www.gov.uk/government/organisations/department-of-health-and-social-care

https://www.hee.nhs.uk/our-work/dementia

https://www.dementiauk.org/for-professionals/how-to-become-an-admiral-nurse/hedn/

https://idea.nottingham.ac.uk/

https://www.ndti.org.uk/

https://www.nice.org.uk/

https://www.gov.uk/government/news/new-mental-health-dementia-and-neurology-intelligencenetworks

https://www.england.nhs.uk/mental-health/dementia/

https://www.rcn.org.uk/clinical-topics/dementia

https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-anddevelopment/dementia/Dementia.aspx

https://www.scie.org.uk/dementia/